

Disability Measurement in the Health and Retirement Study

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INTRODUCTION

The HRS is one of the longest continuous panel data sets in the US with regular survey intervals and consistent questionnaire design. Though it followed an earlier Retirement and Health Survey, the HRS was intent upon measuring health in greater depth than in previous surveys of labor force and retirement behavior. According to Wallace and Herzog (1995) the HRS measures of health were designed specifically to assess the significance of health for work and retirement:

“We focused on a subset of conditions which have public health significance—diseases that are most prevalent among middle aged and elderly persons and/or which are most likely to result in work disability. By tracking these conditions in future waves, HRS investigators will be able to monitor these conditions for their impact on disability, job mobility and job loss, retirement behavior, and mortality” (p. S89)

Two decades ago the HRS was innovative in its attention to disability as a salient aspect of aging and health. The inclusion of detailed task-specific information on functioning was novel in a survey that focused as much on wealth and work as it did on health conditions. The design of the survey acknowledged that one of the most important ways in which health affects worklife and retirement is through the impact of health conditions or injuries on functioning.

The HRS has many unique strengths relative to other surveys measuring late-life disability: the inclusion of a mid-life sample beginning at age 51 (when most aging studies begin at age 65 or 70); the incorporation of a broad and deep amount of information on family relationships, including interviews of both partners in a marriage; retention of sample members that have transitioned from a community to an institutional setting; and of course its signature focus on work, assets, income and debt.

A large number of academic papers have been written on disability using the HRS. According to the HRS website, articles about health have grown over time and now constitute about the same proportion of recent publications as economics and labor combined. Although we have not attempted to summarize or to review the very large literature that makes use of the HRS's disability data, the following very brief depiction of that literature attests to the data's usefulness.

The majority of disability-related information collected in HRS interviews consists of self-reported information on functioning. These disability measures have been used as outcomes in studies of the prevalence of, and trends in, disability in the population as a whole as well as in subgroups (Freedman et al., 2004, 2013; Verbrugge & Liu, 2014), in numerous studies of person-level disability trajectories (Liang et al. 2009; Yang & Lee 2010; Haas & Rohlfen 2010; Wolf et al. 2015; Martin et al. 2015), and for purposes of calculating "active" or disability-free life expectancy (Reynolds et al. 2005; Montez & Hayward 2014). These measures also appear as predictors in studies of a range of outcomes such as poverty status (Duski & Rupp 2013), use of health care services (Bowen & González 2008), or migration (Zhang et al. 2013).

Among couples in which both partners complete HRS interviews, respondents' self-attributions of disability can be used as characteristics of their spouses, allowing researchers to investigate cross-spouse consequences of disablement, in areas such as depressive symptoms (Szinovacz & Davey 2004a, 2004b) or retirement (Johnson & Favreault 2001). Moreover, among those who self-identify as recipients of help from a spouse for daily activities such as eating, bathing, dressing, and so on, it becomes possible to study the correlates and consequences of

spousal caregiving, in domains such as the intensity of caregiving (Lima et al. 2008) or the allocation of time to other activities such as volunteering (Choi et al. 2007).

Disability-related measures collected in the HRS interview also include attributions of disability to each of one's [living] parents. The breadth and specificity of the parental disability information is much less than for own-disability attributes, but these variables have proven to be useful in a diverse set of empirical studies: parental disability (in the form of "needs for care") have been related to one's own depressive symptoms (Amirkhanyan & Wolf 2006), and have been shown to predict hours of caregiving, work, and the intensity of exercise behavior (Arora & Wolf 2014) as well as changes in wealth (Arora 2016). Those same variables have also been used as instruments, to deal with endogeneity of caregiving as a predictor of mental health (Van Houtven et al. 2013).

Today, disability is measured by many different national surveys, and the conceptualization of disability has advanced over the decades since the HRS was first begun, from the disablement process model proposed by Verbrugge and Jette (1994) to the International Classification of Functioning, Disability and Health (ICF) framework (WHO 2001) and subsequent extensions. In this review we will discuss the implications of the evolution of new models for the measurement of domains of self-reported disability in the HRS from physiological functioning (such as lifting or moving objects, or climbing stairs); to task-based difficulties (such as dressing or feeding oneself, or bathing); work limitations; and participation in valued activities. We do not discuss performance measures of physical and mental capacity, sensory impairments (hearing and vision), or cognition. We discuss the use of accommodations such as help from others or equipment and the environment as components

of the ICF framework but consider them as related concepts rather than direct measures of disability. We also devote some attention to some analytic implications and methodological issues related to the design of the HRS including issues around the time periods for which disability is being measured; and the difficulties of measuring disability prevalence, trajectories, and disabling events.

DISABILITY MODELS AND MEASUREMENT IN SURVEYS

The conceptualization of disability is complex. It represents the consequences of health conditions or injuries for functional ability. The causes of disability vary substantially across age groups and even within the older population. Conceptualization of disability has moved over the years from a medical condition located in the individual to a set of deficits that result from the interaction of physiologic capacity with the demands of the physical and social environment.

When the HRS was developed, the most commonly cited framework for disability was the “disablement process” model of Verbrugge and Jette (1994). While the disablement process included environmental and behavioral factors as influences on disability, it was not until the release of the ICF that these were moved to the forefront of a disability model. By the mid-1990s the ICF was in development and it was approved by the World Health Organization in 2001 as a new model of disability that moved away from the focus on disability alone, portraying human abilities as a continuum (WHO 2001). The ICF also expanded the notion of disability to a continuum of ability from highest capacity to profound disablement. It also distinguishes the effects of health conditions on “body functions and structures” from

“activities” and “participation.” The separation of the latter two concepts is not always clear, but the addition of participation to the framework was an important step forward in the understanding about what constitutes disability and is in sync with policy definitions, such as that in the Americans with Disabilities Act, which defines disability as an impairment in a “major life activity”. The ICF is however designed to support the classification of abilities and disabilities rather than to describe a temporal process of disablement.

More recently, the design of the National Health and Aging Trends Study (NHATS) reflects a model of disability that incorporates the ICF concepts but embeds them into a more dynamic model of disablement (Freedman et al., 2011, 2014). The NHATS model places a priority on distinguishing between physical, mental, and sensory *capacity* and “real-life” functional ability. It also brings the component of accommodations (behavioral changes, environmental modifications, independent use of assistive devices, and reliance upon human help) even more to the fore. Distinguishing these concepts is helpful not only in a detailed study of disability trajectories and trends such as the NHATS, but also is an important aspect of disability measurement for the understanding of disability impact. Understanding the extent to which underlying physiologic capacity is changing relative to the ability to manage with disabilities facilitates research on the potential policy changes that could improve quality of life and productivity among aging Americans.

The measures which are used in survey research to operationalize disability reflect our current understanding of disability and empirical research depends upon the adequacy and conceptual clarity of these measures. The causes of disability may be highly varied especially when complex tasks and participation are considered as forms of disablement. Difficulty and

dependence can result from cognitive, sensory, emotional, or physical impairments which themselves can arise from combinations of chronic disease, injury, or dementia. The domains of disability generally measured in surveys are: functional limitations, which measure specific physical body movements; task specific disability (basic and instrumental activities of daily living measures) which assess ability to conduct relatively simple activities of self-care and household maintenance; and work limitations (mainly assessed with regard to benefit eligibility). It is less typical for surveys to obtain information on participation in valued activities unrelated to work or self-care, such as visits with family and friends, cultural activities, sports, and other leisure. In addition, surveys can assess the disabilities of others to whom respondents are related, which the HRS also does.

HRS DISABILITY MEASURES

The HRS survey items relevant to measurement of disablement and disability are numerous and complicated. When the HRS was introduced in 1992, the incorporation of Activities of Daily Living (ADL) & Instrumental Activities of Daily Living (IADL) disability measures was a substantial improvement over the simplistic work limitation questions used in previous studies of health and retirement. These questions focus on basic tasks such as bathing, dressing, toileting and household maintenance. They have been the most widely used in survey research, despite their development for clinical evaluation and focus on distinctions between independence and dependence in activities (Katz 1963; Lawton and Brody 1969). In subsequent waves, the HRS has expanded the set of disability and functional health measures to include

both more basic measures of physical functioning and also the more complex assessments of disability in work and social participation.

Physical functioning and task-specific Activity Measures

In its current form, the main battery of questions (found in Section G of the interview) begin with a series of 12 “functioning” items (sometimes called “Nagi” functional limitations after the epidemiologist who developed them). In all cases, respondents are asked whether “because of a health problem ... you have any difficulty” walking (several blocks; one block); sitting for two hours; getting up from a chair; climbing stairs (several flights; one flight); stooping/kneeling/crouching; extending the arms above the head; pushing/pulling large objects; carrying a 10-pound weight; and picking up a dime. The possible responses to these questions include “can’t do” and “don’t do” in addition to “no” and “yes.” There are several skip patterns embedded in this sequence; for example, only if a person reports having no problem walking are they asked a follow-up question about jogging a mile. Also, someone reporting no problem climbing several flights of stairs is not asked whether they have difficulty with a single flight of stairs. These conditional question sequences were designed to measure variation in the abilities of higher capacity individuals and also to avoid the annoyance to study participants of being asked about basic functioning when they are at the high ends of physical capacity.

Importantly, only those respondents that report “difficulty” with any of the preceding functioning items are asked the next set of questions, regarding a list of 6 Activities of Daily Living (ADLs): dressing, walking across a room; bathing; eating; getting into or out of bed; using the toilet. A second conditional skip pattern is also applied to the ADL items: someone

reporting difficulty doing just one of the several functioning items, and reporting no difficulty dressing (the first of the ADL items) is not asked about the remaining ADLs. The lead-in to the ADL items is slightly different from that of the functioning items, asking whether “because of a health or memory problem ... you have any difficulty...” with the 6 listed tasks. Only for those tasks (if any) for which the respondent reports having “any difficulty” are they then asked whether anyone provides help with that task.

Thus, the HRS, like most or all survey-based measures of disability, relies on its subjects’ subjective assessments of “difficulty,” as well as their judgments regarding the attribution of any such difficulty to an underlying health (or memory) problem. There is undoubtedly a great deal of heterogeneity across subjects in the thresholds—whether of pain or discomfort endured, frustrations demanding patience or coping skills, motivations to carry out or complete a task, or the value attached to one’s independence—beyond which one finds “difficulty” in carrying out a physical task or self-care activity. The existence of this heterogeneity does not suggest a shortcoming of the HRS, and need not cause analytic problems for data users, but does represent a measurement feature that should be more generally understood and appreciated. The use of WHO anchoring vignettes on disability in an HRS module and subsequently in the Internet based American Life Panel has allowed researchers to examine response consistency, thresholds of severity for work disability reporting, and to calibrate comparisons with European surveys (Kapteyn Smith & van Soest 2007; Dowd et al. 2011; Kapteyn et al 2011; Helland and Yin 2015). One way to address the question of heterogeneity in thresholds of difficulty would be to test vignettes like these but for more basic types of functioning.

Disability as “dependency”—the receipt of help from another person—is directly observed only among HRS respondents that report “difficulty” with an ADL task. Data users must, therefore, assume that respondents do not get help from others if the help is not “needed,” i.e., if the respondent can perform the task without difficulty. This aspect of question wording could introduce a downward bias in measures of personal-care assistance received; some past studies have found that a surprisingly large percentage of older people do, in fact, get help performing activities that they could, according to their self-reports, carry out without assistance and also without any difficulty (Wolf, Hunt, & Knickman 2005). This sequence also potentially excludes those who successfully accommodate to their disability with help (or devices) and consequently perceive no difficulty.

The use of assistive devices (called “special equipment”) is only asked for 2 of the ADL items—walking across a room and getting into or out of bed. However, in contrast to the questions about personal help, respondents are asked whether they use equipment or devices when performing the task regardless of whether they reported difficulty with the task or not. The sequence is somewhat ambiguous, however, because difficulty is ascertained separately from equipment use, so it is unclear whether respondents are answering with regard to their difficulty with devices or without (Agree 1999; Freedman 2000; Cornman, et al. 2005).

Following the ADL battery of questions is a series of “any difficulty” questions pertaining to Instrumental Activities of Daily Living (IADLs): preparing a hot meal; shopping for groceries; making phone calls; taking medications; and managing money. Like the ADL questions, these require the respondent to judge whether “because of a health or memory problem” they have “any difficulty” with the activity. The use of a health attribution here is appropriate, as at this

level, task difficulty and accomplishment may be related to many other barriers than health. For example, one may be impaired doing laundry because there is no washing machine at home, or because someone else regularly does that household task (cooking being the most common historical example of a gender based distinction in household specialization).

Changes in question wording, response categories, and skip patterns over time add further complexity to the HRS data. For example, in 1992 (the first wave of HRS) respondents were asked “how difficult” it was for them to perform selected “Nagi” tasks. A separate battery of ADL tasks was not included, but walking across a room, getting in and out of bed, and bathing—activities treated as ADLs in later waves—were included on the list of functional tasks. Moreover, the response categories distinguished among “a little difficult,” “somewhat difficult,” and “very difficult,” in contrast to the simple yes/no distinctions introduced later. The practice of skipping over the ADL items for respondents with no reported physical functioning difficulties was also introduced in a later wave.

These sequences of disability-related survey questions have been stable since 1996 (for the HRS) and for the combined HRS-AHEAD (and later) cohorts since 1998, the first year in which the sample includes all community-dwelling individuals age 50 and older. For users wishing to make use of the earlier information, the documentation that accompanies the RAND-HRS version of public-use data (Chien et al. 2014) includes an abbreviated but very helpful summary of cross-wave consistency issues. Despite the existence of resources such as these, data users (not to mention reviewers and editors) should be aware of the many subtleties associated with the use of HRS data on disability, and also be aware of the ease with which a data user can overlook inconsistencies that might undermine longitudinal analyses.

Work related disability and employer accommodation

The HRS arrived almost concurrently with the Americans with Disabilities Act (ADA), authorized in 1990 and implemented in July 1992. The ADA was an important piece of civil rights legislation that prohibits discrimination against individuals with disabilities, especially in the workplace. It was amended and reauthorized in 2008, after the courts eviscerated many of its provisions. The 2008 ADA Amendments Act (in effect from January 1, 2009) was intended to strengthen the legislation and broaden its definitions of qualified individuals, but virtually nothing is known about the effectiveness of the reauthorization or its impact on work and retirement.

One of the key features of the ADA was the requirement that (most) employers provide reasonable accommodation to workers with disabilities so that they can be hired or remain on their jobs after the onset of a disabling condition. According to Von Schrader et al. (2014) the HRS is one of only three national surveys to ask any questions about employer accommodations and the only one reflecting the near and post-retirement age group. The HRS thus provides an important and unique opportunity to understand disabilities in the context of the work environment and how the progressive development of disabilities in mid-life affects the retirement process.

Although there has been some research on work limitations and on the relationship of occupational injuries and workplace characteristics to disability and early retirement, very few studies have used the HRS to study employer accommodations and most were published in the 1990s using the baseline and first few follow up waves. Richard Burkhauser used the HRS to examine the impact of employer accommodations, and his study remains the only one we are

aware of that specifically uses the first wave of the HRS to represent pre-ADA conditions. He found that employer accommodations slowed the speed of application, and that the effect was larger in models treating the accommodations as endogenous (e.g. Burkhauser 1999). Other studies showed that in 1992-94 the prevalence of employer accommodations for currently employed individuals with arthritis was as low as 20% (Yelin, Sonnebom, and Trupin 2000). This finding was confirmed by a more recent longitudinal study using HRS waves through 2010 (Hill, Maestas, and Mullen 2014) which showed that only about 25% of workers with new work limitations were provided with any employer accommodations.

Questions on work limitations and employer accommodations have been asked in every wave from 1992 through 2014. They are found, interestingly, in a section titled “disability,” currently section M in the questionnaire. Questions on work limitation appear to be unchanged since 1992. The section begins with the question “Do you have any impairment or health problem that limits the kind or amount of work you can do?” Respondents reporting a limitation are asked to attribute it to a health condition, whether the impairment is temporary (less than three months) and whether they have experienced the limitation previously. From 1992 through 1998 those who report no work disability (and since 2000 those under age 70) are asked whether “... any impairment of health problem limit[s] the kind or amount of work [they] can do around the house” (question M006 in 2014). Interestingly, in the HRS this “housework” item is being asked separately and uses different wording from the housework items in the IADL battery, and is being asked of those under age 70 rather than the full age range. We are not aware of any studies that have used both the IADL measures and the “housework” limitation item; it would be interesting to investigate the overlap of these two closely-related

behavioral domains. Finally, if respondents answer “no” to the housework question they are asked if they experience *any* activity limitations. Later questions ask about the timing of the limitation, its effect on work, and whether the condition is expected to improve.

The “disability” section is long and was probably originally designed to sort individuals into eligibility categories for disability benefits. In fact, most of the questions in this section are about the receipt, type, and amount of benefits. However, we would argue that the design of the section undermines the goal of facilitating rigorous scientific study of work related disability and accommodations and limits the study of predictors of disability benefit application and receipt.

The first concern is that the initial question about work limitations determines who will be asked questions about workplace characteristics and employer accommodations. Similar to issues that have been raised with other disability questions, if subsequent items are conditioned upon the report of a limitation, there is a negative selection for those with greater levels of disability and likely misses entirely those who have been successfully accommodated for disabilities that could affect their work. Wittenberg and Loprest (2007) point out that 42% of respondents newly reporting a work limitation reported that their health problem began to interfere with work more than two years earlier, though they did not report a work limitation in their previous interview.

Since the enactment of the ADA, employer accommodations for disability need to be understood in relation to the legislative mandate. While the ADA requires reasonable

accommodation by *most* employers for *qualified* employees¹, it is incumbent upon the employees to notify employers of their disability and to request an accommodation. In fact, employees have input on the type of accommodation they need. There is no way to know whether the presence or lack of accommodations is a function of employer characteristics or whether the employee has chosen (due to stigma or fear of retribution) not to reveal their disability or request accommodation.

Questions in the HRS about employer accommodations include personal assistance; shorter work days; change in hours; breaks and rest periods; ‘special’ transportation; changes in job responsibilities; training; ‘special equipment’ and rehabilitation. Similar to the work limitation questions, accommodations are asked only of those reporting a work limitation and only among those who answer affirmatively to an initial question about whether “at the time your health started to limit your ability to work your employer did anything special to help you out so that you could stay at work.” This selects for those who consider job changes to have been specially designed to respond to their changing abilities, and also is confounded by the need for employees to request accommodation.

These sequences of questions are anchored in outdated conceptualizations of disability as resulting from discrete recognizable events, they ignore the role of successful accommodation, and do not take into account the complex process of accommodation resulting from the ADA requirements. This section also is not designed to integrate with the more sophisticated and

¹ To be protected under the ADA, an individual must have, or be regarded as having, a substantial restriction in performance a major life activity such as hearing, seeing, speaking, breathing, performing manual tasks, walking, caring for oneself, learning or working. In order to qualify they also must be able to perform the essential functions of the job.

detailed measures of disability (and disease and assistance) found elsewhere in survey. This is a missed opportunity to promote research on work limitations and employer accommodations that takes into account the more detailed understanding of the physical, cognitive and sensory impairments investigated elsewhere in the HRS, and to facilitate research relevant to federal legislation promoting equal access to persons of all abilities.

Participation

Participation is defined by the ICF as “involvement in a life situation,” and thus is potentially vast in scope. Among the many specific indicators of participation mentioned in the ICF and covered, to varying degrees, in the HRS are driving, informal social relationships, family relationships, community life, and recreation and leisure. As in other domains that we have reviewed, the HRS “participation” indicators vary over time. For example, a question on the respondent’s ability to drive has appeared consistently from 1995 onwards. A question about the frequency with which the respondent “... get[s] together with ... neighbors just to chat or for a social visit” appears in all HRS (but no AHEAD) interviews, although with differing response categories over time.

Beginning in 2004 there have been several participation items covered in the so-called “leave-behind” interviews, to be filled out by respondents on their own time and later mailed back to the survey’s main field office (for details on the first two waves of leave-behind questionnaires see Clarke et al. 2008). Among the items included in these survey components are questions about the frequency with which respondents attend meetings or programs of groups, clubs, or organizations; how often they “meet up” with, speak to, or write to children, immediate family members (e.g., brothers, sisters, parents, cousins, or grandchildren) and

friends; and (beginning in 2008) participation in volunteer activities. Response rates for the mail-back questionnaires differ from those of the main survey, adding another complexity that must be faced by data users.

These participation items are potentially very useful in empirical research; not only can they serve as indicators of reduced functioning or capacity—i.e., as a type of “disability” indicator—but they also can be viewed as predictors of later health and functioning, appealing to various theories of social connectedness and health (Cornwell et al. 2008; Latham et al. 2015). Our examination of the HRS’s online bibliography suggests that these items have received relatively limited use, at least in comparison to the Nagi, ADL, and IADL activity measures discussed above. In addition to the analytic issues mentioned in the previous paragraph, several of these items require care in the coding of outcome variables: for example, the response categories for the “how often...” items are “3 or more times a week,” “once or twice a week,” “once or twice a month,” “every few months,” “once or twice a year,” and “less than once a year or never.” If an analyst wished to measure a reduction in social participation as a potential consequence of declining physical function, they would have to address the fact that a “reduction” could occur yet no change in the reported frequency of visits or conversations could be observed.

The preceding discussion has dealt with behaviors related to participation in activities valued by the respondent and thus resulting from individual choice or agency. However, participation in both necessary and valued activities can be influenced by or constrained by the environment.

Environmental components of disablement

Any review of disability measurement would be incomplete without some attention to the role of the environment in assessing disability. As highlighted in the ICF and other recent models of disablement, it is now broadly accepted that what manifests as disability is the product of an interaction between individual capacity and environmental demand. Disability researchers have, over the past decade, focused greater attention on distinguishing the physical, mental, or cognitive capacity of an individual from the ability to function within the challenges of their environment (Iezzoni & Freedman 2008)

Thus measuring the disability of individuals and understanding its impact means understanding disability in its environmental context. The context that has been the most studied with regard to late life disability is the home. This focus has relevance to the most severe levels of disability in basic activities of daily living, but does not address the effects of accessibility on disability in work and in participation.

In the HRS in Section H (Housing) there are a small number of questions about the home environment including the type of housing, the number of floors, whether living space and bathrooms are on a single floor, and the need to use steps to get into and out of the house. For those who are aged 65 or older (or whose spouse is 65+) questions H139-H145 ask whether their home has been modified to make it easier or safer for an older person or someone with a disability to live there and what types of modifications were made. Since 2010 the section also asks about the out of pocket costs of adding or changing home features and installing items such as grab bars. These questions were integrated into the core questionnaire after being tested in an experimental module in 2006.

The separate collection of information on the existence of such features and on their use is important and appropriate, since modifications can be put in place for another household member, such as a spouse, or in anticipation of future needs. Use by the respondent of features such as ramps, railings and grab bars are assessed in section G for two of the ADLs discussed above—inside mobility and transferring.

Other studies (e.g. the National Health and Aging Trends Study) may be better positioned to collect detailed information about the use of devices and home features for all activities, but the HRS is well positioned to collect information on the costs of such equipment and modifications, especially since they are primarily paid for out of pocket. The questions included in the housing section give some information about the costs to individuals which can be examined to better understand costs of care.

The potential environments in which an individual with disabilities may function is theoretically infinite. There is no objective way to collect information on the barriers or features that affect participation in leisure activities or other forms of social participation. However, subjective questions about the sources of difficulty or limitations on participation could be collected. For working respondents, information on the existence, costs, and use of accommodations could be incorporated in questions about workplace disability and accommodations, extending our understanding of ways that mild to moderate levels of disability could be managed through environmental change or through technological assistance.

Parents' disability measures

An unusual and very valuable feature of the HRS is its sequence of questions that elicit

information on each of a respondent's parents functioning and care needs. A parent's "need for care" can be determined using three survey questions: "does [your mother/father] need help with basic personal needs like dressing, eating, or bathing," "can [your mother/father] be left alone for an hour or more;" and "has a doctor ever said that [your mother/father] has a memory-related disease?" The first 2 of these questions were asked beginning in 1995 (for the AHEAD cohort) or 1996 (for the HRS cohort). The "memory related disease" question was first asked in 1998; it was replaced by two questions in 2010: "Has a doctor ever told your mother (or father) that she (or he) has Alzheimer's Disease" and "Has a doctor ever told your mother (or father) that she (or he) has dementia, senility or any other serious memory impairment?" These questions are repeated for each of R's living parents.

Prior to 2002, a single "family respondent" was designated to provide data about own parents, as well as parents-in-law (and other extended-family relatives). The "in-law" items can be merged to the individual-level data provided by the "nonfamily" respondent, producing a complete file of records on own parents and parents-in-law for all respondents. Beginning in 2002, each respondent (in particular, both members of a married or partnered couple) answer their own "parent need" questions.

Thus, there are several issues of longitudinal consistency associated with the "parent need" items, just as for the own-disability items discussed before. We are not aware of any methodological research addressing the comparability of the single cognitive-decline measure used prior to 2010, and either or both of the pair of cognitive-decline questions introduced in 2010. Nor are we aware of any attempt to address the relative measurement properties of one's own, compared to one's spouse's, reports about a mother's or father's needs for care or

assistance. Methodological studies along these lines, if they could be undertaken, would undoubtedly be of considerable value to the data user community.

Although these parents' care needs items have been used in several studies, one problematic feature of these items, in the context of intergenerational caregiving, merits special mention. Following the sequence of questions on parents' care needs is an extensive battery of questions about each respondent's provision of help to one or more parents. An HRS respondent's caregiver status (an indicator variable) and caregiver intensity (a continuous measure of hours of care) can be determined using questions of the form "did you [or your spouse/partner] spend a total of 100 or more hours [in the last 2 years] helping your _____ <mother, father, deceased mother, deceased father> with basic personal activities like dressing, eating, and bathing?" [the 100-hour minimum threshold—approximately 2 hours/week on average—was imposed in order to reduce respondent burden (Soldo and Hill 1995)]. If a respondent answers this question affirmatively, then the identity of each person helped is ascertained and, for each person helped, the respondent is asked the total number of hours of help spent giving such assistance over the 2-year reference period.

A problem produced by this question wording is the difficulty of calibrating an HRS respondent's parental caregiving behavior with the parental needs to which it presumably is a response. With the 2-year "window" to which caregiving pertains, the parent receiving the help could have had care needs at the beginning of, or at the end of, or at any (and possibly all) times during this 2-year reference period. Moreover, the parent that received the care may have died during the 2-year interval. In contrast, the "need for care" items discussed above refer, at least implicitly, to the time at which they are asked (i.e., "now"). Consequently, it is

possible that an HRS respondent helped a parent “with basic personal activities” yet that same parent was not reported to “... need help with basic personal needs...” at either the current nor the preceding interview. This, in turn, creates what is a minor paradox in the context of HRS data: while it is possible for a respondent to (legitimately) care for a parent that does not “need” care (as indicated using the relevant questionnaire items), it is not possible for a respondent to receive care unless they have “difficulty” (which can be interpreted as “needs”) with that activity.

METHODOLOGICAL ISSUES

A broad array of survey design issues falls under the heading of “methodology,” and many of these issues are of particular relevance to research on disability and the disablement process. It is well-known, for example, that proxy respondents and self-respondents often provide different information about whether someone is living with a disability (Santos-Eggimann et al. 1999; Iezzoni et al. 2000; Todorov & Kirchner 2000; Yasuda et al. 2004), although some studies have found high levels of agreement between proxies and self-reporters (Long et al. 1998; Lyons et al. 2002). Similarly, even among self-reporters, the answers to questions about disablement may differ when the interview is conducted in person rather than by telephone (Wolf et al. 2007; Kelly-Moore 2006); here, as well, the evidence is mixed, with one study, based on HRS data, finding no differences by mode of administration (Herzog & Rodgers 1999). Because the HRS allows proxy respondents, and also uses both telephone and in-person modes of administration, data users need to be aware of these design features and their implications for empirical findings. We will not comment further on these two

methodological issues. We do, however, devote some attention to 2 other issues, namely the use of temporal reference periods, and the distinction between disability status and disabling events.

Reference Periods

In our discussion of the different measures of disability in the HRS, we have noted problems across sections in the implementation of a reference period for respondents. By a reference period we mean the specification of a time period for which respondents are asked to report disability or disability-related behaviors. Reference periods are important because disability and disabling conditions are rarely completely stable. They can ebb and flow, become progressively worse, or in some cases be completely resolved with recovery from disability.

In section G, measuring functional limitations and ADL limitations, there is an introduction to each set of questions asking respondents to report difficulties that they have “now” (where the reference to the present time is implied rather than explicit) but to “... exclude any difficulties that you expect to last less than three months.” The exclusion is mentioned only once, before the first question in each sequence, and it is not clear whether or how well respondents remember the stem of the question and apply the criteria across each of the individual tasks. In the work limitation section (M) respondents under age 70 who report limitations are asked to attribute the limitation to a health condition and whether the condition is “a temporary condition that will last for less than three months”. These items are cognitively challenging for the respondent, asking for both recall and forecasting of ability. Imposing a reference period – especially one that entails predictions about the future –introduces potential measurement errors or bias.

Beyond methodological issues, the use of a three-month criterion for disability is neither meaningful nor justified. The use of a 90-day criterion to identify “chronic” disability can be traced back to the screener developed in the early 1980s for the National Long Term Care Survey (NLTC). The purpose of the NLTC was to study health and long term care issues among those with substantial and irreversible disabilities, and the window was intended to exclude anyone with temporary conditions from the survey entirely. Gill and Gabhauer (2005) compared monthly questions about disability with the three-month assessment and found that one-third of respondents meeting the NLTC criteria for disability did not actually report disability over three consecutive months (their gold standard)².

For analytic purposes it is important to be as consistent as possible in the use of reference periods for interrelated disability concepts. The receipt-of-help items that follow the “difficulty” questions mentioned above are worded as follows: “... does anyone ever help you _____?”. Respondents may interpret the term “ever” quite broadly; and the three-month reference period specified in the “difficulty” questions need not line up perfectly with the receipt of help, thanks to the nonspecific reference period implied by the receipt-of-help items. In the case of exit interviews (which elicit information about deceased prior HRS respondents), the “got help” questions refer to the last three months of life. Note that a living HRS respondent may report on whether he or she “ever” gets help in what is later revealed to be one of the last 3 months of his or her life. In the subsequent exit interview that we would expect to find for a respondent in this situation, the informant for the exit interview may

² It should be noted that Gill and Gabhauer use a question about the need for help rather than difficulty for their gold standard monthly questions, so the comparisons are not completely comparable.

answer questions about help receive in the (former) respondent's last 3 months of life that contradict the previous respondent's contemporaneous report of the receipt of help. Contradictory data can, of course, be generated even in high-quality surveys; this is simply an illustration of the type of data-analytic difficulty that the HRS design may encourage. In contrast to the end-of-life items, the intensity-of-help items (which appear in a loop of questions starting with G070) ask about the amount of help a living HRS respondent gets, from the helpers that "ever" help them, but does so only with respect to the last one month. With respect to that one-month reference period, for each helper the interview asks both "how many days" (in the last month) and how many "hours per day" the helper spends providing that help.

Given the complexity of balancing appropriate and consistent reference periods, some attention should be given to this aspect of question design and its analytic implications. Simply eliminating the reference periods will not resolve the issues, as they can be explicit as they are here, or implicit if time is not mentioned. People do a very poor job of remembering how long they have experienced disability and with a few exceptions (for permanent injuries or progressive conditions) have little basis to anticipate how far into the future their condition will continue.

Disability status, events, onset, recovery, and duration

The two-year interval between core HRS interviews is a long-established feature of the study's design. Together with the choices that have been made regarding question wording, especially with respect to the physiological functioning and activity-restriction items central to the measurement of disability, this design feature places a number of restrictions on the types

of analyses that the HRS can properly support. Despite the qualification, found in the lead-in to both the Nagi and the ADL questions, whereby respondents are directed to “... exclude any difficulties that [are expected] to last less than three months,” these indicators provide only a point-in-time measure of functional or activity limitations. When a respondent reports “difficulty” in any of these items in two successive waves of HRS interviews, there is a possibility that at some point between the two interviews they had no such difficulties. Similarly, the absence of difficulty in two successive waves of HRS interviews is not sufficient to rule out the presence of difficulty at some point between those interviews. On the other hand, if at wave “one” someone reports no difficulty with a task or activity, but at wave “two” (2 years later) they do report difficulty, there has clearly been (at least one) instance of disability “onset.” Conversely, a report of difficulty, followed two years later by a report of no difficulty, can reasonably be interpreted as evidence for “recovery” of function.

The issues exposed by these features of the HRS design pertain to the distinction between disability status and disabling (or recovery) events, and to the potential for determining the duration of time spent in a given disability status (or, between “events”). We contend that disablement may, but need not, proceed through an unfolding sequence of “events.” For some of the diseases or conditions that underlie disablement, such as dementia or arthritis, there may be no clear-cut events separating an episode of full functioning from an episode of diminished functioning. For others, however, such as stroke, falls, or other injuries, there can be a well-defined event, marking a clear transition between disability statuses. With respect to disability status, the HRS provides a wealth of point-in-time measures spread out over 2-year intervals. With respect to disabling events, the HRS provides only limited evidence (in the form

of reports of the occurrence of strokes, falls, and so on). Nevertheless, some papers have appeared that treat “transitions” between successive-status indicators as an indicator that there has been exactly one disabling event (e.g., Montez and Hayward 2014). Several papers provide evidence on the problems—mainly, a substantial bias in estimates of transition rates—associated with the assumption of “no missing events” (Wolf & Gill 2007, 2009; Freedman et al. 2015). For the same reasons spelled out above, a sequence of identical biennial measures of disability status should not be treated as a measure of the duration of disability.

SUMMARY AND RECOMMENDATIONS

In reviewing the HRS measures of disability we find that the study is providing a comprehensive set of measures of self-reported disability and related concepts. The instruments include measures of each of the components of current conceptual models of disability, though there are some potential analytic pitfalls for users. The exception to this is in the work limitation section, which is underutilized, poorly integrated to the overall survey, and embodies limited and outdated concepts of work limitations.

Our review prompts us to suggest three areas for attention by the HRS team with regard to measurement of disability: the analytic implications for data users of the disability-related survey design issues we have highlighted; benefits of new methodological studies; and possible additions or changes to consider for future waves of HRS data collection.

Analytic Implications for HRS Users

The HRS is a complex survey designed to allow measurement of disability at different levels. Users need to be cognizant of subtleties of data organization that have analytic implications, especially the hierarchical skip patterns incorporated into the primary disability sequence. We recognize that these patterns were introduced in order to improve the interviewing process and take into account reporting in prior waves, but they may be confusing to those with less experience.

The availability of the user-friendly RAND public-use datasets is beneficial and has reduced some of the pitfalls for naïve users but also increases the potential for mistakes in interpretation. RAND researchers have appropriately applied the assumptions in the derivation of the summary measures that upon which users rely. However, documentation does not always make clear how these decisions affect the use of the variables. For example, in the RAND-HRS file all the people that are skipped from the questions about personal help because they reported no difficulty are coded as “missing-skipped” and a new user might treat these as simply missing, rather than skipped.

The fact that the HRS can be used to create measures of disability that are consistent with the ICF and other new disability models does not mean that users translate these into meaningful studies. There are many insights into the relationship of disability and retirement that could be addressed but which have been understudied because of the dominance of ADL/IADL measures. It is a potential opportunity for the HRS to encourage the broader researcher community to take greater advantage of the richness of the HRS data on disability. A new workshop focused on these relationships, perhaps in conjunction with the Michigan based

Demography of Aging Center, would potentially open up new and more innovative use of the data.

Potential Methodological Studies

We have annotated a number of issues related to item wording and measurement of disability. In doing so, we have raised questions about the meaning and analytic interpretation of these measures, rather than suggesting that there are flaws in the very well-thought out design of the HRS. The HRS investigators have a long history of rigorously evaluating survey content including the functioning measures (e.g. Fonda and Herzog 2004) and we recommend that this tradition be continued with some new examination of the physical functioning, ADL and IADL measures.

Some topics identified in our review that would be worthy of investigation include: an examination of the hierarchical skip patterns that lead to pre-assignment of a “no difficulty” response in several functional limitation and ADL items; testing the use of vignettes (possibly in an experimental module) to uncover otherwise unobserved heterogeneity in respondents’ “difficulty” thresholds; cognitive testing to investigate the meaning to respondents of the three month reference period in the ADL and work limitation sections; and a study of the consistency of own- and spouse’s reports of parents’ needs for help.

The HRS team might consider undertaking their own methodological studies along these lines; alternatively, they might convene workshops aimed at drawing the larger community of HRS users (and potential users) into these research efforts.

Possible Changes or Additions in Survey Content

While we are mindful of the many constraints associated with adding new survey content, two specific areas seem particularly deserving of attention:

First and most noteworthy, we suggest a comprehensive review of Section M on work disability and benefits in order to integrate it with the other disability measures in the survey and also to facilitate research relevant to the current policy environment. It is possible that the section could be streamlined to reduce the number of “disability” questions, relying on coordination with measures from the functional limitations and ADL/IADL sections of the questionnaire. Any such reduction in items would allow the potential introduction of more salient and consistent questions on employer accommodations and the employment impact of disabilities.

The assessment of caregiving hours among respondents who are providing help to parents would be improved by addition of a reference period during which care is provided. This could be accomplished with little impact on the overall survey length by asking only those who report that they provided help in excess of 100 hours over the past 2 years, whether any of those hours of help were provided in the last month. This would enhance the ability to match care provision with care receipt by HRS respondents, and also facilitate studies that examine the relationship of caregiving hours with labor force hours.

CONCLUSION

The HRS is a unique and valuable resource for the study of aging and disability. Its design incorporates measures of the major components of current disability models, enhanced

by information on work, assets, and family. One of its greatest strengths is that it is one of the only national studies of aging to sample the population below age 60. While the impetus for this design was to better understand influences on the process of retirement, it is an important advantage with regard to the study of disability. The onset of conditions that contribute to disability, such as arthritis, hypertension, diabetes, tends to begin earlier than the administrative definition of “old age” at age 65. This advantage is increasingly important to understand anticipated (but unknown) changes in disability levels for younger cohorts as they age. Studies of mid-life disability have shown increasing levels of obesity and disability among new cohorts that may have more negative implications as they age. HRS added Early Baby Boomers (EBB, born 1948–53) in 2004 and Mid Baby Boomers (born 1954–59) in 2010, giving it unique strengths to study these upcoming changes. Understanding these trajectories will be important for the estimation of health care costs and our understanding of the life course factors that contribute to late life physical and cognitive functioning.

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